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# Femininity, Dependency, and Patriarchy: The Marginalization of Women With Japanese Encephalitis and Neurological Sequelae in the Northern Terai Region of Uttar Pradesh

Katherine Ehrenreich  
*SIT Study Abroad*

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**Femininity, Dependency, and Patriarchy:  
The marginalization of women with Japanese encephalitis and neurological sequelae in the  
Northern Terai region of Uttar Pradesh**

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Spring 2013

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## **ABBREVIATIONS AND ACRONYMS**

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AES	Acute Encephalitis Syndrome
ANM	Auxiliary Nurse Midwife
ASHA	Accredited Social Health Activist
BPL	Below Poverty Line
CHC	Community Health Center
CMO	Chief Medical Officer
CMS	Chief Medical Superintendent
JE	Japanese encephalitis
MoHFW	Ministry of Health and Family Welfare
MOIC	Medical Officer in Charge
NTD	Neglected Tropical Disease
PHC	Primary Health Center
UP	Uttar Pradesh
WHO	World Health Organization

## **ABSTRACT**

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The present study seeks to determine how girls and women who have suffered from neurological sequelae after a Japanese encephalitis (JE) infection are marginalized in the Northern Terai region of Uttar Pradesh, India. Societal and familial values were studied in comparison to behaviors towards a neurologically disabled girl after a JE infection in order to determine how women infected with JE are excluded from cultural practices and norms. The

study was conducted in the Northern Terai region of Uttar Pradesh in the districts of Bahraich and Shravasti under the guidance of DEHAT and Dr. Jitendra Chaturvedi. Semi-structured interviewing was utilized in gathering primary information; informants included parents of JE infected children, teachers, community leaders, and medical professionals. It was found that women suffering from neurological sequelae following a JE infection were excluded from the institution of marriage, inflicting a burden onto the natal family. This exclusion from marriage strips a woman of her feminine identity as perceived by the community. Hinduism was additionally identified as assigning blame to the victim through the notion of karma. The incomprehensiveness of India's JE Vaccination Campaign denies coverage and information of JE to remote populations, thus creating a need to empower and educate communities on both their rights and how to break the transmission cycle.

## **INTRODUCTION**

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Neglected Tropical Diseases (NTDs) disproportionately affect the world's poorest people, and are the leading causes of "chronic disability and poverty in low- and middle-income countries." NTDs primarily affect children and women of reproductive age, robbing them of their health and economic aptitude (Hotez and Pecoul, 2010). The *PLOS Neglected Tropical Diseases Journal* defines Japanese encephalitis as a viral infection among NTDs, along with Dengue, Yellow Fever, and Rabies (PLOS, 2013). The World Health Organization (WHO) has identified a list of the top 17 NTDs to be targeted for disease management and transmission control around the world (WHO, 2013). Japanese encephalitis is excluded from this list of top 17 NTDs, yet remains to be one of the leading "kid killer[s]" in Uttar Pradesh, India (Ghosh and Basu, 2009).

Japanese encephalitis (JE) is a viral infection that affects humans and animals, and is the leading cause of Acute Encephalitis Syndrome (AES) in Asia (Ministry of Health and Family Welfare, 2010). It is transmitted by mosquitoes belonging to the *Culex tritaeniorhynchus* and *Culex vishnui* groups (WHO, 2001). These mosquitoes breed exclusively in stagnant water, particularly in flooded rice fields. The disease burden has increased in the past 20 years due to intensification of irrigated rice production systems in South and South-East Asia, as the flooding of fields at the start of monsoon season results in an “explosive build-up of the mosquito population” (WHO, 2001). The virus reproduces in pigs, and is circulated among ardeid birds (herons and egrets); thus, the increase of the mosquito population during monsoon season causes the virus to circulate between the original animal hosts to the human population at rapid rates (WHO, 2001).

JE is caused by a virus that affects the membranes around the brain. Disease is typically characterized by “rapid onset of high fever, headache, neck stiffness, disorientation, coma, seizures, spastic paralysis and death” (WHO, 2001). Among all of eastern and southern Asia, approximately 30,000-50,000 cases and 15,000 deaths are reported annually, although inadequate surveillance may result in an underestimation of this figure. About 30 percent of cases are fatal, and 50 percent result in permanent neuropsychiatric sequelae. As of 2008, about 1,000 children were dying of JE every year in the Indian state of Uttar Pradesh (Ghosh and Basu, 2009).

### ***Classifying Outcomes of JE***

Due to the nature of this study, it is difficult to narrow down the most common classifications of disability due to JE. While children with JE observed in villages had apparent neurological complications and many physical impediments, villagers were not informed of the

medical terms for these disabilities, yet they were able to describe them. Additionally, MOICs at two district level PHCs were unaware of disability classifications of JE patients, as suspected JE cases are referred to the district hospital level (PHC Medical Officer, Personal Interview). At the district hospital level two pediatricians and a CMS were interviewed, while a CMO was unavailable for interviewing. When asked what the most common classifications of disabilities are, a list of many complications was given. These included paralysis, abnormal behavior, speech disorders, epileptic episodes, and cranial nerve palsy. While informants at the village level did not use such medical terminology, these types of symptoms were described among others.

Additionally, JE patients are typically discharged from the hospital after recovering from the acute phase of illness, and are usually lost to follow-up. Particularly in North India, the ability for rural families to regularly follow-up with the district hospital is contingent on the family's economic capacity for travel, among other factors. Thus, knowledge on a patient's "profile of neurological sequelae, recovery or persistence of deficits" remains unclear for an overwhelming majority of rural patients (Baruha et al, 2002). Therefore, for the purpose of this study, the term *neurological sequelae* will be utilized in classifying the complications of JE, as specific terminology will be utilized when possible. Neurological sequelae is defined "as any or a combination of severe motor deficit, blindness, severe hearing or speech impairment, epilepsy, behavior problems and cognitive impairment that impair[s] daily activities or play" (Idro et al, 2010). While JE also causes many physical impairments, this study will primarily focus on cases with apparent cognitive impairments, while specifics of those disabilities are typically unknown by the child's family beyond description.

While male and female children are equally burdened by the incidence of Japanese encephalitis, the social consequences suffered by girls and women are significantly greater and



unique to the Indian context. According to Maya Kalyanpur, women and girls with disabilities in India are “one of the most marginalized groups in society,” looking towards explanations of patrilineage and “strong son-preference” that make women victims of discrimination and abuse (Kalyanpur, 2008). The purpose of this study is to determine how girls and women who have suffered from neurological sequelae after a Japanese encephalitis infection are marginalized in the Northern Terai region of Uttar Pradesh, India. The study is organized to determine how women with JE are excluded from societal, familial, and cultural values and practices. Such exclusion is based on the institutions of marriage, feminine roles, and attitudes towards disability among the Hindu religion.

### ***Field Study Objectives and Methods***

The present study was conducted in the Northern Terai region of Uttar Pradesh, on the border of Nepal. The study took place over a four week period in the months of April and May 2013. I resided in the Bahraich district, and conducted a majority of my fieldwork in the Jamunaha block of Shravasti district and Mihinpurwa block of Bahraich district. These two districts were chosen due to their high prevalence and incidence of JE. Both districts were identified by the Ministry of Health and Family Welfare (MoHFW) as among the 60 high priority districts in the country affected by JE and Acute Encephalitis Syndrome (AES) cases (MoHFW, 2013). In 2006, the Ministry of Panchayati Raj named Bahraich as one of the 34 most backward district of Uttar Pradesh, which is receiving funds from the Backward Regions Grant Fund Program. The Northern Terai region is additionally comprised mostly of “backwards castes” (The Indian Express, 2012).

While the study was conducted during wheat harvesting season, this did not appear to significantly affect my fieldwork. Because a majority of informants were the caregivers of

children, they were not involved in the harvest and resided mainly at home. A particular challenge faced throughout my study was the availability of transportation, as well as the condition of roads suitable for four wheeled vehicles. The most common mode of transportation was forbidden for SIT students, at times making it more difficult to locate a vehicle and a driver.

My informants for the study included parents of children who suffered from a JE infection, teachers of infected students, community leaders, as well as medical professionals. My informants were deliberately chosen in order to gain an understanding of how those directly affected by Japanese encephalitis perceive the disease and its social consequences. Locating informants was done with the help and organization of DEHAT. Most of the informants were located prior to my arrival to the village, while some were located by asking community members if they knew anyone with *dimagi bukhar*, or brain fever. Consent was gained from the informant before the start of each interview after explaining my role as an American student studying the social impacts of Japanese encephalitis. Permission was sought to record the interviews for transcribing purposes, while one PHC medical officer requested not to be recorded. The names of all informants have been omitted in this paper in keeping with promises to ensure anonymity. Interviewing methods consisted of semi-structured interviews, which allowed for flexibility in catering to each family's experiences.

I faced several challenges while conducting interviews as a foreigner in rural Indian context. While it was necessary and incredibly helpful to have a translator at all times, the presence of a translator appeared to distract from the intimacy of the interview. I was not able to have a direct conversation with many of my informants due to the fact that they would respond directly to the translator, causing the interview to feel structured and at times tense. In order to mitigate the tense atmosphere, I gave my introduction in Hindi for every interview, along with

using a Hindi name to introduce myself. This usually prompted laughter among villagers and allowed for a smoother transition into the interview. Another issue pertaining to the language barrier was simply that I spoke English and was American. While I was very clear that I was only a student and merely no one of importance, my presence at times seemed to cause confusion and apprehension.

Throughout the interviewing process, I found more ways to mitigate the tense atmosphere. My interview questions touched on very sensitive topics, such as the prospect of marriage for a JE infected child and the ways the community treated a disabled daughter or son. However for many of my interviews, half of the village was crowded around, making the informant visibly reserved and nervous. Efforts to have more private interviews, as well as having the presence of female community leaders to ease the anxiety of mothers were infinitely helpful. I additionally encouraged my informants to ask anything they wanted to know about me at the end of each interview in order to allow them to be the interviewer.

As a foreign student, I was unaware of many dynamics and cultural cues throughout my interviews. I was initially concerned that my informants would only respond with two or three sentence answers, causing me to believe I was making them uncomfortable. When I inquired about this to DEHAT staff, I was given the explanation that due to their illiteracy, they cannot elaborate on their emotions and their views. Their “limit” is two or three lines. While I attribute this “limit” to be in part due to illiteracy, I expect my interviews to have been more at length in the absence of language and ethnic barriers. Some of my most successful interviews were with community leaders who were comfortable discussing such topics of marriage and sexual abuse among chronically disabled women. Yet my interviews with village families were incredibly insightful and valuable.

## **GENDER RELATIONS AND PATRILINEAGE IN NORTH INDIA**

In order to contextualize the present study, a brief overview of gender relations and patrilineage is given. Patriarchy, as seen throughout the world, is a social system in which social organization is central to the role of the male as “the primary authority figure” (Princeton, 2013). Therefore, fathers control autonomy over women, children, and economic and material resources. Patriarchy is contingent upon female subordination, which further perpetuates a norm of male rule and privilege. In the North Indian context, practice of exogamous marriage further perpetuates the notion of male dominance. Women are traditionally expected to marry outside of the family, in which they subsequently move in with their husband’s family. This places them in an inferior position within the household hierarchy. As noted by Rahman and Rao in their article, “The Determinants of Gender Equity in India: Examining Dyson and Moore’s Thesis with New Data” (2004), a wife has the potential to build her power and status within the household overtime, yet women lose the “protection” of the natal family, leaving them completely subordinate in the early stages of marriage.

Such patriarchal norms additionally assign lower economic worth to females in the household. Many economists argue that women’s lack of authority over household decisions is due to their limited contributions to the household budget (Rahman and Rao, 2004). However, it could also be argued that cultural norms prevent the extensive movement of women from the household, a direct reflection of hierarchical authority, thus deeming them incapable of significantly contributing to the household income. However, the overwhelming lack of participation of rural North Indian women in the labor force both lowers their intrinsic worth

within the household, as it perpetuates their vulnerability in the case of conflict within the household. As will be mentioned throughout this paper, Anthropologist Sherry Ortner analyzes the universal proximity of men to culture as women are to nature. The social roles of women in proximity to nature are constructed by their physiological functions, insofar that such functions are confining to social contexts, which are also seen as being closer to nature. For example, the physiological role of lactation defines the woman's social function within the household and society. This responsibility confines women to the household for functional purposes, as well as the responsibility to socialize children (Ortner, 1974). Men, however, are representations of culture as they create technology and symbols that are "lasting, eternal, transcendent objects," while women create human beings; thus, "perishables" (Ortner, 1974).

### **PATRIARCHAL SOCIETY AND THE PROSPECT OF MARRIAGE: A BURDEN TO THE NATAL FAMILY**

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In Indian societies, as in many societies around the world, women have a distinct domestic role. This role is a marker of identity, as fulfilling this role is an indication of womanhood. Marriage is the key to fulfilling the traditional household roles that are expected from women, yet the responsibilities of a wife and mother are perceived as unattainable for women suffering from neurological sequelae. This section will focus primarily on the denial of marriage to such women, and its impact on the natal family. The social and emotional impacts of this denial will be discussed in the following section.

#### ***The Female Role***

At the time of marriage in the Hindu religion, women vow that they will be the caretakers of the home and family. This includes children, spouses, parents, and relatives who have illnesses. These responsibilities are seen as "an extension of their reproductive nurturing roles" (Habib, 1995). Once a young girl has suffered from Japanese encephalitis, a subsequent

neurological disability deems her the responsibility of a caregiver. Thus, her potential as a wife and mother is greatly minimized as she is not perceived capable of being a carer herself. The inability for a woman with this classification of disability to marry is recognized as a great burden for the natal family.

The mother of an 18 year old boy with severe neurological complications after being infected with JE described the difference between having a son and a daughter with JE. “If it was a girl it would have been worse. What would she have done? It’s a boy so he can stay here. The problem is that she won’t be able to get married. If she is married [with this disability], how will she take a bath? What will she do during her period?” (Mother of 18 year old boy with JE, Personal Interview). The inability for a cognitively disabled woman to take care of her own body without some form of assistance makes her unsuitable to perform any “womanly duties.” Thus, she loses her physiological roles of motherhood. Asserted in Simone de Beauvoir’s The Second Sex, “The woman is adapted to the needs of the egg rather than her own requirements;” rather, the woman’s body is enslaved to the reproduction of the species (de Beauvoir, 1949).

From an anthropological perspective, women are subscribed to the roles of nature, as men are to culture, as argued in Sherry Ortner’s 1974 article *Is Male to Female and Nature is to Culture?* Adopting Ortner’s viewpoint, women are valued in society in proximity to their ability to fulfill their perceived roles. The mother’s physiological roles deem her responsible for bearing children, breast feeding, and socializing children in the early years of life, which transcends into the woman’s social roles. The social roles of women in proximity to nature are constructed by their physiological functions, insofar that such functions are confining to social contexts, which are also seen as being closer to nature. As aforementioned, the physiological role of lactation defines the woman’s social function within the household and society. This responsibility

confines women to the household for functional purposes, and is exacerbated by the responsibility to socialize children. This association with the “domestic circle” brings women closer to nature not only through the lactation process, but additionally through the association between children and nature. This association is seen through the un-socialization and dependency of young children, which is universally recognized as the responsibility of women (Ortner, 1974). Thus, a woman’s supposed incapacity to cater to the needs of her “egg,” or child, due to her perceived inability to fully care for her own body, makes her unbefitting to participate in the institution of marriage.

Patriarchal kinship structures generate sex-based hierarchies that greatly affect disabled women and marriage. If a man is unable to find a wife, his last option is a disabled woman (Community Leader, Personal Interview). Consequently, the subordination of the woman is intensified at the start of marriage. Her disability is a defining factor of the marriage, thus magnifying her “flaw” and potential of vulnerability. It is additionally important to note that the needs of the male are put ahead of the female. His need to find a wife has solidified the marriage, rather than the needs of the woman. Furthermore, while it is rare for a disabled woman to marry in India, it is “common to see disabled men married to able-bodied women, who often find themselves fulfilling the role of dedicated carers for the lifetime of their partners” (Habib, 1995). Again, the needs of the male counterpart are prioritized. While women with disabilities are marginalized from the institution of marriage, disabled men are more likely to benefit from the nurturing roles of women.

Moreover, a general consensus was gained from village families that it is more socially acceptable for a boy to not marry than a girl. The father of a 13 year old girl with JE and severe neurological sequelae expressed his concerns for his daughter. “She doesn’t understand anything;

marriage will definitely be a problem. It's more of a headache when it's a girl with *dimagi bukhar* because nobody wants to help. But with a boy, it's okay if he doesn't marry, and much less of a headache. He would stay at home and help with the farming" (Father of teenage girl with JE, Personal Interview). In patriarchal society, the son is expected to stay with the natal family after marriage, and the daughter goes to the household of the husband. Therefore, it is considered a burden if a daughter stays home unplanned. This burden is manifested economically and socially, as well as by principle that she is meant to belong to another household.

### ***Something that is Not Yours***

"In any case, she is *paraya dhan*, something that is not yours, because she's supposed to belong to somebody else's house. If the girl had been married, she would have had her own family. She would have been taken care of" (Community Leader 1, Personal Interview). As explained by a village community leader, one of the biggest problems with JE infected girls not being able to marry is that they are breaking the patrilineal cycle. Not only is this an unexpected burden for the natal family, it is also socially stigmatizing. This burden and stigmatization is not solely due to the unique needs of a disabled daughter; it is greatly due to the perceived violation of the social fact that is a patriarchal society. As defined by Emile Durkheim, a social fact is comprised by "the beliefs, tendencies and practices of the group taken collectively" (Durkheim, 1982). Thus, social facts have implications within economic, religious, political, social, and familial spheres of society.

Gender-based hierarchies are the grounds of many social facts in North India, including marital traditions and the sending of the daughter to her husband's household. This social fact, as all social facts are, is a mode of function. The prevention of a daughter to marry deems a deviance from the social fact. As A.L. Kroeber argues, the "ideal values of society always suffer



in actual human living of them,” and such deviance results in irrationality within culture (Kroeber, 1949). From both familial and communal perspectives, the remainder of a daughter with the natal family after marriageable age is not only abnormal, it is irrational.

The concept of *paraya dhan* plays a significant role in how cognitively impaired women are treated by the natal family in comparison to disabled sons. When asked how a daughter with JE would be treated differently than a son with JE, a village community leader responded, “[The parents are] ready to work more to treat a boy, make him better, spend more money and make more effort for a boy because he can provide them returns; the boy will take care of them further down the line. It’s an investment. Girls they won’t do that for, she’s already somebody else’s” (Community Leader 2, Personal Interview). Because the social role of a woman is assigned to her roles as a wife, a girl with disabilities is both incapable of marriage and economic contribution. The family does not see the economic benefit in investing in her education and treatment, as opposed to a boy who may not marry, yet is still capable of generating an income as doing so is prescribed in his social roles. In the absence of marriage as a realistic option for a girl child, the natal family awaits a life-long burden that will be ensued upon them.

### ***Familial Dynamics and the Mother and Father-in-law***

While a prominent hierarchical structure exists among caste and gender in North India, hierarchies exist within kinship structures and among women. Marital status and the position within the family are defining factors for the status of women, and often mimic patriarchal behaviors and relationship amongst women of a household (Murthy, 2004). Women with neurological sequelae following a JE infection are further marginalized from the prospect of having a respected position in the household. Depending upon the severity of sequelae, there are multiple possibilities for the outcome of marriage. The father of a teenage girl with severe

complications from JE expressed his concerns for her marriage. “If you don’t understand the concept of who the father-in law is and who the mother-in-law is, there is no point in getting married. She doesn’t understand anything at all. When she has no brain, what can we do?” (Father of teenage girl with JE, Personal Interview). In this scenario, the natal family has recognized her incapacity to understand the importance of a mother and father-in-law due to the severity of her complications, deeming marriage to be out of the question.

However, it is common for women with mild to moderate mental disabilities to be married with the “inducement” of higher dowry (Habib, 1995). These women are at higher risk for suffering from power dynamics within the household from the father or mother-in-law. An example given by a village community leader was of a cognitively impaired woman (the cause of her impairment was unknown) who married a “normal” man. The household left her and returned the dowry when they came to realize she was unable to complete her duties and comprehend the power dynamics within the household. Rather, she did not respect the mother and father-in-law in a fashion that was expected of her (Interview #, 24 April 2013).

Another possibility described by many villagers is the marriage of a mentally challenged girl who is disrespected by her in-laws. “They don’t feed her properly because she cannot do anything. They don’t talk to her nicely; they behave very badly towards her, like she’s a dog” (Community Leader 2, Personal Interview). This description was given by a village community leader in reference to an adult woman who developed a cognitive impairment after marriage. He did not know the cause, but compared the symptoms to JE.

The ability for power dynamics within the household to occur revolves around social relationships that are systematically denied to cognitively impaired women. Nevertheless, women who do not suffer the burden of a disability are marginalized through “limited freedom

of movement, limited opportunities to make household decisions, [and] little control over economic resources” (Sengupta, 2003). However, this position improves with age as they climb the “multigenerational” hierarchy. Additionally, the strength and security of North Indian women within the household is typically synonymous to the power held by her husband or male counterpart of the household (Sengupta, 2003). Thus, women who are prevented from marrying, in the case of JE infected girls and women, are prevented from climbing a social hierarchy. Rather, they are prey to hierarchical dynamics within the household, never achieving the power or status of a mother or mother-in-law. If marriage is in fact achievable, it may be inferred that the husband is also of a lower hierarchical status that he has settled to marry a disabled woman, in which case husband and wife perpetuate each other’s low social standing.

One interview was conducted with a young woman whose family believed she had Japanese encephalitis. She had gone to a district hospital where she was ignored for not being able to pay, so she turned to local treatments where she is being treated for her bad spirit. Her in-laws were present during the interview, who answered all the questions while the daughter-in-law sat on the ground with her face covered. They explained loudly and seemingly frustrated that she is not able to carry out any of her duties when her headaches come, and they also believe her to have given the illness to her 10 month old child (Parents-in-law of woman with suspected JE, Personal Interview). While this is not a confirmed case of JE, the community and family speak of and treat it as JE, demonstrating how the perception of JE affects household power dynamics. When asked to speak to the young woman alone, the mother and father-in-law looked confused, responding that any questions can be asked in front of them. While the young woman was not able to be interviewed, observations of power dynamics were strongly apparent. Particularly when they spoke of her incompetence to complete her duties, a diminishment of her confidence

could assuredly be inferred. As put by one DEHAT Project Coordinator (Personal Interview), “If you’re not doing your regular work as the family expects, you suffer in the family. So this mental power is increasing, and she loses confidence.”

## **DEPENDENCY AND FEMININITY: UNFEASEABLE COEXISTENCE**

When a woman crosses the marriageable age and remains unmarried in rural North India, it redefines her role in society. Mentally disabled women have the double burden of being unsuitable for marriage, as well as being perceived as dependent upon the natal family. According to a village community leader in reference to how a girl would suffer from JE, “If you cross marriageable age and you’re still not married, then your status gets lower, because you become dependent. *Adhin*, dependent” (Community Leader 2, Personal Interview). As a result of patriarchal gender constructions, an unmarried daughter is the primary responsibility of female family members, thus assigning her the role of a child dependent on the nurturing roles of women. Additionally, such dependence strips a woman of her feminine identity, diminishing both her potential of fulfilling any feminine roles, as well as her confidence.

### ***Less than Woman***

The ability to climb the social ladder as a rural Indian woman is dependent upon her ability to birth, nurture, and socialize a child, especially if that child is a boy. Motherhood is a creator of an identity that is unachievable by any other means. In Anita Ghai’s article, “Disabled Women: An excluded Agenda of Indian Feminism” (2002), Ghai defines motherhood as a fulfillment of a woman’s status. She asserts,

Disabled women are, however, denied the possibility of this fulfillment, as marriage and consequent motherhood are both difficult achievements in a socially restrictive environment. The denial of women's "traditional roles" to disabled women creates what Michele Fine and Adrienne Asch (1988) term "rolelessness," a social invisibility and cancellation of femininity that can impel disabled women

to pursue, however hopelessly, the female identity valorized by their given culture but denied to them because of their disability.

In the particular case of Japanese encephalitis victims, neurological damage such as paralysis, intellectual deficits, speech disorders, etc., prevent many woman from being perceived as nurturing and feminine. According to a village community leader, if a woman suffers from neurological complication of JE, “[society] stops treating her as a woman; [society] treats her even worse, even lower than woman” (Community Leader 2, Personal Interview).

As cognitively disabled women are perceived as being in need of care themselves, it diminishes them to a status of “less than women” (Addlakha, 2007). Such women are seen as the receivers of nurture and care, thus they cannot possibly provide care themselves. Disability is often perceived as “eternal childhood,” as regarded by Ghai. Victims of Japanese encephalitis are uniquely preyed to this term, as JE disproportionately affects children between the ages of two and 15 years old (District Hospital CMS, Personal Interview). Thus, if a young girl is infected with JE during childhood and does not fully recover, she will maintain her childlike appearance through her needs of care and protection, interpreted by society as dependence. As aforementioned, Sherry Ortner asserts it is the mother’s physiological and social roles to socialize her young children who display behaviors of dependency. The association of disabled persons with dependency and childlike behaviors prevent such women of being capable of fulfilling her societal roles as an adult woman, making her less than woman.

### ***The Female Body and Sexuality***

For every family interviewed, nearly two dozen, the same response was given when asked how a JE infection would affect a girl differently than a boy: “She won’t be able to get married. That’s a big problem.” “Why is that a problem?” “What will she do? We are here for now, but what will happen when we are not here anymore?” After re-framing the question in

several ways, the same answer was always given without elaboration. Interviews with community leaders allowed for deeper discussion on sexuality, domestic violence, and the female body.

In a quest to discover the difference between the burden of an unmarried boy and an unmarried girl, several community leaders articulated reasons attributable to female anatomy and a patriarchal society.

If they're not married, the mother or father can take a boy for the bathing and to the latrine. But as a girl grows and begins menstruation, only the mother can take care of her, the father won't. So if the parents have passed away, and the boy is staying with his brother, the brother can take care of him. But if a daughter was staying with the brother, the brother will definitely not take care of her, so it is now left to the sister-in-law. Whether the sister-in-law does that or doesn't do that is a big question. (Community Leader 1, Personal Interview)

Here it is identified that women face an increased burden of disability in comparison to men that is attributable to the biological physicality of women. Due to menstruation, as well as patriarchal norms, a man is not permitted to assist a woman with her hygienic needs. Because women belong to the husband's family after marriage, it is not socially acceptable for a disabled woman to live with her married sister. Thus, she must live with her brother after the death of her parents, and is the responsibility of the female figure in the household. Such norms reiterate the notion of the eternal child through the exclusive dependence on a female figure.

Through displayed behaviors of dependence, perceived as the eternal child, women with neurological sequelae are considered sexually inept by much of society. According to one DEHAT Project Coordinator (Personal Interview), "Sexually, girls are inferior to men. There are fears of sexual harassment if she doesn't marry; it's thought she will be safer if she is married." From this perspective, a married woman not only belongs to her husband, she is regarded as being sexually active. A neurologically challenged woman, however, is perceived as un-woman,

or asexual. Such stereotyping results in disabled women as a “sexually disenfranchised segment of the population. There is, in fact, a general social rejection of their sexuality” (Addlakha, 2007).

The topic of sexuality in the Indian context is alarming for both able-bodied and disabled women. When asked how a JE infection could affect a woman’s sexuality or risk of sexual abuse, a district hospital pediatrician stated, with nervous laughter, “Sexual abuse happens even with normal girls. The risk is even higher if she is disabled” (District Hospital Pediatrician, Personal Interview). One village girl, whose age and cause of neurological disability was unknown, was raped by fellow community members. While the cause of her disability was unknown, one outcome of neurological sequelae after a JE infection is speech disorder. The girl described was recalled as not being able to speak properly, deeming her vulnerable, unable to tell her caretakers of the incident (Community Leader, Personal Interview).

While disabled men and women share the burden of being viewed as sexually inferior, disabled women are subject to a double discrimination. As aforementioned, women are predisposed as sexually inferior in North Indian society, whereas men carry cultural and sexual dominance. Disability diminishes women’s already inferior roles, particularly women of rural, low-resource settings with no access to rehabilitation facilities (Habib, 1995).

Michel Foucault’s work *Discipline and Punish* (1975) is additionally illuminating in the context of gender relationships and sexual dominance. In this piece of writing, Foucault explains the discourse between discipline and punishment as modes of control, insofar that discipline asserts control by forcing an individual or group to fit certain roles, while punishment utilizes a direct infliction of pain to gain control. Foucault is firm in his assertion that these forms of power are asserted based on the knowledge they produce, insofar that “there is no power relation

without the correlative constitution of a field of knowledge” (Foucault, 1975). Thus, power asserts prescribed gender relations, which perpetuate power dynamics. This is seen explicitly in the context of sexual authority over neurologically compromised women through the use of rape and physical dominance.

### ***100 Rupees a Day***

The economic dependence of a neurologically compromised woman exudes another form of reliance which relinquishes a woman of her femininity. Japanese encephalitis, among many other NTDs, disproportionately affect the world’s poor. Thus, the parents of an infected child are typically not in financial positions to provide regular treatment, perpetuating the severity of both infection and subsequent neurological sequelae. As argued by Ghai, “For poor families with a hand-to-mouth existence the birth of a disabled child or the onset of a significant impairment in childhood is a fate worse than death. It is truly the proverbial last straw on the camel's back, jeopardizing the entire family's existence” (Ghai, 2002). It is important to note that the initial economic instability of families to pay for treatment results in a child or adult whose economic dependence is intensified due to lack of treatment.

Several families gave accounts of economic instability which greatly hindered treatment options. One father sold a portion of his paddy field to pay for his five year old son to see a doctor. Because this particular village, among many neighboring villages, does not have land rights, its inhabitants are not recognized as citizens by the government. Thus, the family paid full price, 12,000 rupees, to be seen by the doctor in the absence of a BPL card. He currently is not paying to continue his son’s medication. “I work hard as a daily laborer on 100 rupees a day. If you get labor, it’s fine. If you don’t, you go hungry. Now [my son’s] voice is not clear and his right hand and right leg are not strong enough; he won’t be able to work” (Father of five year old



boy with JE, Personal Interview). While this example is of a boy with JE, it demonstrates the perpetuation of the disease burden. A family living on less than US\$2 that is not able to treat the infection, or maintain proper medication after the acute phase of illness, exhibits a demographic that lacks the self-sufficiency and education to break the transmission cycle.

While women traditionally are financially dependent on their husbands or adult sons, as defined in a patriarchal society, cognitively disabled women are economically dependent on the natal family, defying normative female roles. Therefore, what becomes an economic burden for both the woman and her natal family, is additionally a source of de-feminization. Her economic dependence on the natal family further perpetuates her child-like perception among the community, deeming her unsuitable to integrate into society as a socially acceptable woman.

## **HINDUISM AND COMMUNITY PERCEPTIONS: ASSIGNING BLAME**

Karma, as understood in Hinduism, refers to intentional and moral actions that influence one's fortunes in both this life and the next (Encyclopedia Britannica, 2013). While the scope of this paper will not allow for an in-depth analysis of the Hindu religion, the notion of karma will be explored at the surface level. Karma is a way of explaining instances of evil and misfortune, particularly for those who appear undeserving of their misfortune. Misfortune is thus attributable to wrong actions committed in a previous life. In the context of a child, particularly a girl child, suffering from a Japanese encephalitis infection within the Hindu community, that child and her family are remarked as having committed a wrong action in a previous life. Such perceptions influence communal behaviors and perceptions of the child and her family.

### ***Karma and the Charity Response***

In the Indian context, “disabled people sometimes are depicted as suffering the wrath of God, and being punished for misdeeds that either they or their families have committed” (Ghai,

2002). A common perception among villagers in the Northern Terai region of Uttar Pradesh fixated on the misdeeds of the family whose child has suffered from a long-term cognitive impairment. In the eyes of the community, such a cognitive impairment resulting from a JE infection is not merely a neurological complication; it is a “flaw.” In a patriarchal society, as previously explained, being born a girl creates a double burden for the disabled woman. She must suffer the wrath of the stigma of her disability along with the stigma of being a woman (Ghai, 2002). In the context of Hinduism and karma, particularly in rural North India, “if a girl is born, that is considered a bad thing, or a sign of bad karma. If a girl has a disability, that is considered even worse” (Community Leader 2, Personal Interview). From a lens of Hinduism, a JE infected girl or woman has become a victim of her own offense, rather than a victim of poverty.

Along with the assignment of blame towards cognitively impaired women, karma influences the community response towards those of misfortune. The charity and philanthropic response are prominent among response to disability in India, particularly among the Hindu community. Such charitable gestures are not necessarily manifested out of commitment to the rights of disabled persons, yet these gestures are a “response to a cultural expectation to one’s dharmic (religious) duty toward the needy” (Ghai, 2002). However, disabled persons become unintentionally (or intentionally) excluded from full participation in religious institutions, insofar that they are the receivers of that institution’s charity. In this sense, disabled persons, particularly disabled women who are most in need of economic support, are further marginalized from full societal participation.

## *Community Perceptions*

While Hindu values influence the charity response among the community, the stigma associated with both cognitive disabilities and bad karma greatly influence the way community members behave towards JE infected individuals who have suffered from neurological sequelae. One grandfather of a JE infected teenage girl expressed his concern for the other girl in the family. As he perceives the community's response to his granddaughter's illness, the younger sister may also not be married because the JE infected daughter is a "social insult." According to the girl's father, "Nobody really understands. This is a backward area; people want nothing to do with her" (Father of teenage girl with JE, Personal Interview). As aforementioned, A.L. Kroeber argues the "ideal values of society always suffer in actual human living of them" (Kroeber, 1949). While the charity response is a reflection of Hindu values, such responses were found less common among villages visited during fieldwork. According to one village community leader, "If the village has to help they will do it once. They cannot take care of their own children, forget about other's children" (Community Leader, Personal Interview). This is again a reminder of the struggles and vulnerability of villagers in rural North India. Neurological sequelae following an infection of JE are unique to the poor and marginalized of India, insofar that they are the victims of neglected diseases, as well as the victims of an incomprehensible vaccination campaign<sup>1</sup>. Thus, such disabilities are due to a preventable disease. Disabled persons who belong to less marginalized demographics or urban areas with many resources are more likely to represent a subject of the charity model.

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<sup>1</sup> India's vaccination campaign for JE will be covered in the Discussion section of this paper

## **DISCUSSION: HUMAN RIGHTS AND VACCINATIONS**

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As any feminist would argue, women's rights are human rights, and human rights are women's rights. While the social structure of patriarchy is essentially nonmalleable, the human rights issues pertaining to neurologically compromised women are mendable on medical and educational levels. The Government of India is currently in the process of a vaccination campaign to eradicate JE, yet the campaign has shown little comprehensiveness. Additionally, little effort is made in the follow-up and rehabilitation process following the acute phase of illness. As little effort is made by the government, minimal awareness of JE is seen throughout the Terai region among resource poor inhabitants, particularly women. This section will seek to uncover the current vaccination strategy and its failure to cover the target population, as both observed through fieldwork and perceived by community members and one medical professional.

### ***The Current Strategy***

Vaccination campaigns were implemented by the Government of India following a massive outbreak of JE in 2005 in the states of Uttar Pradesh and Bihar. By 2009, 30 districts were targeted for the campaign, which targeted children between the ages of 1 and 15 years old. The original campaign was scheduled to continue through 2010 in order to cover 109 endemic districts, followed by a Routine Immunization Program (MoHFW, 2010). Additionally, between the years of 2003 and 2009, Uttar Pradesh remained the highest of 16 endemic states with the highest count of combined AES and JE cases and deaths. In 2009, 3,073 cases and 556 deaths were reported in UP (MoHFW, 2010).

However, accurate JE surveillance data is difficult to achieve due to "difficulty in making a clinical recognition of the disease" (MoHFW, 2010). A shortage of sufficient laboratory

support is also a problem that has been recognized by government. In recognition of these fundamental barriers, the vaccination campaign is an attempt to decrease both the disease burden, as well as those in need of proper laboratory facilities. The current campaign primarily focuses on the strength of vaccination teams and sites. Vaccination sites are based at service delivery level, and require safe injection storage and delivery, as well as accessibility and acceptability to the target group. Vaccination teams are comprised of ANMs, ASHAs, teachers, and volunteers (MoHFW, 2010). The campaign is organized sensitively and comprehensively in order to reach the target populations, particularly rural, resource poor settings. Yet, this seemingly comprehensive program has failed to execute itself properly, as gathered from the opinions of villagers and medical professionals.

### ***Problems of Implementation***

A village teacher and mother described in vivid detail the death of her two year old son from a JE infection (Personal Interview). When asked if her other son was immunized for JE, she responded, “He has had all of his immunizations.” At the end of the interview she asked, “Do you know if there is a vaccination for JE? How do I get it so the same thing does not happen to my other son?” As both the mother of a JE victim and an educator, this woman’s awareness of JE and her options to protect her children represents a majority of the Northern Terai region of Uttar Pradesh, as well as many of the study’s informants.

In two separate interviews with two PHC Medical Officers, the figure given of JE patients per year was one to four, for that particular PHC. They suggested speaking to the district hospital, where all suspected JE cases were referred. When speaking to the district hospital Chief Medical Superintendent (CMS) and two pediatricians, the numbers given were 70 suspected cases and 22 serum positive cases of JE in 2012. They expressed confidence that the vaccination

campaign is working properly; stressing that JE is in fact no longer a major problem for the district. When asked why so many of the study's informants had been unvaccinated and did not know how to obtain a vaccination, the response given was, "Ask the CMO" (District Hospital CMS, Personal Interview). The CMO, however, requested to postpone his interview to a time inconvenient to me due to transportation.

After these three sets of interviews, the true incidence rate of JE was of great uncertainty. NGO supervisors, for example, insisted there were more cases in the district hospital than the figure given. Furthermore, the number of families identified at the village level suffering from JE indicated one to four cases per year at the local PHC was inaccurate. While not all interviews are directly referenced in this study in order to avoid repetition, approximately 20 families were interviewed with confirmed or perceived JE cases, with many more unable to be interviewed due to time constraints. Additionally, most families reported recent infection in the past one to two years.

A final interview with a private general medical practitioner in Bahraich offered an alternative perspective. The problem, he says, is typical of all Indian Government programs. "They are not serious of their job, and they do not do their work. These programs do not reach the people in need [...] This campaign should have been over by last May" (Private General Practitioner, Personal Interview). He additionally estimates the district hospital has between 200-300 cases of JE every year. Any government employee, he says, especially the CMO and CMS of the district hospital, will never record the true number of cases of JE, as it is a demonstration of their own failure. As an alternative, many JE patients are put into the category of meningitis. In reference to the vaccination campaign, the general practitioner stressed the importance of proper storage of the vaccine. Most PHCs and CHCs do not have reliable electricity, preventing

the vaccine from being properly stored in a cool environment (Private General Practitioner, Personal Interview).

### ***Prospects of Rehabilitation***

Among an incomprehensible vaccination campaign, district hospital pediatricians highlight the need for rehabilitation services for neurologically impaired children following a JE infection. When asked how a JE infection would socially impact a girl child during marriageable age if she suffered from neurological sequelae, the question was not entertained. “Marriage? Rehabilitation comes first” (District Hospital Pediatrician, Personal Interview). It was made clear that any hope for a child survivor of JE was through rehabilitation. Yet, how does one reach rehabilitation services from a remote village? If the father only earns 100 rupees a day, will he miss a day of labor to take his daughter three hours away by motorbike to rehabilitation at the district hospital? This is not only a question of economic capacity, but a question of female worth. In an economically limited environment, the infection of a girl child may be seen as a lost cause, as her rehabilitation will not provide immediate economic benefits to the family. While the long-term social impacts of JE are most damaging to a family’s economic and social standing, many families must think in a short-term time frame, as limited income and countless vulnerabilities do not allow for long-term economic spending.

If parents are unaware of the importance of the JE vaccination, children become further powerless in their susceptibility to JE. Once infected, rehabilitation services are not economically and geographically available. Thus, the cycle begins of powerless children, particularly girl children who become victims of patriarchal oppression and household hierarchies.

## ***A Human Rights Approach to Break the Transmission Cycle***

While the vaccination campaign has sought to prevent the human infection of JE, the current campaign will neither break the transmission cycle nor educate rural inhabitants on the risk factors of JE. A lack of economic and political power of populations living in remote areas hinders their access to information on how JE is transmitted to the population, which directly relates to many inhabitants' livelihoods. Earlier mentioned, JE is reproduced in pigs, which are very prevalent among rural farming populations. As rice production in India has increased, the prevalence of stagnant water in flooded rice fields, particularly among monsoon season, is a defining factor in the breeding of mosquitoes and increased incidence of JE. The formation and education of farmers' groups in areas with irrigated rice production is an approach that empowers the farmers, allowing them to take their health into their own hands. Additionally, educating both men's and women's groups on the availability and importance of vaccinations, as well as the proper use of bed nets.

Women's and farmers' groups are pre-existing in many communities, allowing for feasible education at community meetings. Such education of improved farming techniques, strategies to avoid and address stagnant water, and the importance of vaccines are not topics that are easily comprehensible and sustainable after short-term interventions. Long-term, community involved interventions empower the community, creating sustainable awareness. A vaccination strategy which fails to both reach and educate the population is a neglect of human rights. The neglected population is not equipped with the information and education needed to make informed choices about their health, and is additionally unable to recognize their exclusion of a vaccination they are unaware of.



In addition to the importance of women's groups, the inclusion of disabled women in these groups is vital not only for JE affected women, but for the greater disability movement in India<sup>2</sup>. While the disability movement in India has prompted action in many urban settings, rural areas have yet to see the benefits of these efforts. The ability for disabled women to participate fully in women's groups is a way to abolish their appearance of dependency, along with increasing their confidence and motivations to be active participants in society.

## **CONCLUSION**

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Japanese encephalitis, among many Neglected Tropical Diseases, disproportionately affects the world's poor, particularly those who lack the social and economic mobility to prevent disease and seek care. Due to limitation of knowledge and resources, many rural inhabitants are unable to categorize the outcome of disability, yet are able to describe certain symptoms. In this case, the outcomes of JE are described as neurological sequelae in the absence of medical categorization by those interviewed. In patriarchal North Indian society, women are subscribed to particular domestic and feminine roles. However, the onset of JE and its subsequent neurological complications are shown to exclude a woman from the institution of marriage, thus inflicting a burden onto the natal family, as well as stripping a woman of her feminine roles and identity. Such exclusion from society results in the rolelessness and asexuality of such women, as well as economic dependence. Beliefs of karma within the Hindu religion act as an additional mode of marginalization, as they blame the victim for her own misfortunes.

The target population of this study demonstrated limited access to health care resources, as well as limited knowledge of the JE vaccination and vaccination campaign. A human rights approach of education and community empowerment is suggested in order to achieve full

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<sup>22</sup> The scope of this paper does not allow for full discussion and analysis of the disability movement in India. It is, however, important to note the exclusion of women within the disability movement and its implications on women's rights particularly in rural settings.

vaccination coverage and break the transmission cycle of JE. This long-term approach to empowerment will lessen the disease burden, as well as the social impacts for girls and women.

## **SUGGESTIONS FOR FURTHER STUDY**

Suggestions for further study include a long-term case study following JE infected girls as they enter reproductive and marriageable age. The current study gathered perceptions of family and community members on the social impacts of JE as they pertain to women. However, there were no women in the community with confirmed JE cases, as the recent increase in cases has affected primarily children. A following into adulthood of girls currently infected would be much more revealing of the social impacts and marginalization experienced by women and their families. A long-term anthropologic study would additionally gather deeper insight and information into cultural practices and norms which influence such social impacts, as the current study was held to a four week period.

A closer surveillance of the vaccination campaign would be additionally illuminating in determining the populations and geographic areas that do not reach care. This is a more difficult study to achieve as it pertains to a government campaign, which proved to reveal minimal information in the current study.

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## **APPENDIX**

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Interviews were semi-structured and based off of basic questionnaires. The questionnaires are as follows:

### **Medical Officer/Medical Professionals**

1. How many cases of JE do you see during the peak and off seasons?
2. What is the demographic of the patients? What are their ages?
3. How many patients survive with a disability?
4. What are the most common classifications of disability from JE?
5. How do you think these types of disabilities will socially affect children?
6. How will girl children be affected by these disabilities as they enter marriageable age?
7. How do rural communities perceive JE and its outcomes?
8. How comprehensive is the vaccination campaign? Is it effective?
9. Why do you think so many cases still occur?
10. How can the campaign be made better?

### **Parents of Children**

1. Can you describe your child to me and when he/she showed symptoms of JE?
2. At the time of infection, did you know the signs of JE?
3. What did you do when that happened?
4. Does your child have any behavior changes or other kinds of changes from JE?
5. How have those changes affected your family?
6. What are your concerns for your child's future?
7. (If boy) How do you think this would affect you and your child differently if it was a daughter with JE?  
(If girl) How do you think this would affect you and your child differently if I was a son with JE?
8. Are there things other girls can do that she won't be able to do?
9. How has the community reacted to your child's disability?

### **Teachers**

1. What differences do you see between children with JE and "normal" children? Can you give an example?
2. Do you see any differences in how girls and boys with JE are treated?
3. Do children stop coming to school when they have JE?
4. How many of your students show signs of JE every year?
5. How do you think the outcomes of JE will socially affect children as they age? Is it different for boys and girls?

### **Community Leaders**

1. How will the outcomes of JE affect women as they reach marriageable age?
2. Has there been any discrimination against cognitively disabled women in the community?
3. How are girls/women and their families economically marginalized after a JE infection?
4. How is a girl with JE a burden on the natal family? How is that different for boys?
5. How does a JE infection influence women's ability to meet their feminine roles?
6. Have cognitively impaired women been common victims of rape and violence?
7. How has Hinduism and karma played a role in the community's reaction to a child with JE?